Country visit – Ireland

Objectives of the country visits

The objective of the TEHDAS country visits is to provide an overview of the status of national health data management in different European countries. This mapping exercise takes place in the form of country visits in which national stakeholders working with health data or exchanging health data are interviewed.

The Joint Action Towards the European Health Data Space (TEHDAS) supports EU member states and the European Commission in developing and promoting concepts for the secondary use of health data to benefit public health and health research and innovation in Europe.

When did it take place?

The visit to Ireland took place virtually between **3 and 6 May 2022.**

Who was involved?

8 stakeholder organisations were interviewed: Central Statistics Office (CSO), Department of Health (DoH), Economic and Social Research Institute (ESRI), Health Information and Quality Authority (HIQA), Health Research Board (HRB), Health Service Executive (HSE), Private Hospitals Association, National Office of Clinical Audit (NOCA).

Any questions?

Contact us at TEHDAS.sciensano@sciensano.be
Information about all country visits is available on tehdas.eu/country-visits

Ireland in brief

The Irish Health Information System (HIS) has some valuable data sources, but many are fragmented and siloed. The health system is not fully digitalised, with both paper and digital records. The public healthcare system is tax-financed. The Health Service Executive (HSE) is responsible for provision of public health and care services. There is high uptake of private health insurance. A large proportion of health services are provided by the private system. A unique identifier for health (Individual Health Identifier) was introduced in 2014, however it has not been fully deployed and its usage for linking data is currently limited. There is significant work ongoing to develop the technical infrastructure and governance framework for the HIS.

Data collections/sources

- The national metadata catalogue includes over 120 data collections and collated sources of information.
- There is no national electronic health record (EHRs). Hospitals use different systems which are only interoperable to a degree, mainly through the national messaging broker. There is currently no integrated patient management system in the community. The eHealth Ireland programme aims towards coordinated health information systems across the HSE.
- HSE collects community and hospital level data. Community data tends to be operational and aggregated.
- Data from public hospitals is collected in the Hospital Inpatient Enquiry (HIPE). Hospital-specific medical record numbers are used, tracking episodes of care rather than patients. There is limited reporting from private providers.
- The Department of Health is responsible for the Healthy Ireland survey. The Central Statistics Office (CSO) hosts the Irish Health Interview Survey.
- Health Research Board (HRB) hosts 4 national data collections. Many other data sources exist, including disease-specific registries (e.g., National Cancer Registry).

Data quality

- HIQA is the independent authority for improving health information and quality (remit for public providers).
- HIQA develops recommendations to support decision-making. It drives improvements in data quality by developing national standards/guidance and assessing compliance. It also develops learning resources to assist health and social care providers improve the quality of their data and information.
- Quality control mechanisms appear to be mainly manual, with some automated controls, e.g.:
- HIPE data undergoes rigorous checks/audits.
- NOCA has a tool to ensure that data matches the standards implemented, and a validation process.

Data infrastructure

- Data storage is decentralised. A national metadata catalogue of national data collections is hosted by the HIQA. An update is ongoing.
- The Irish Social Science Data Archive (ISSDA) has a catalogue of surveys and social science data. Some individual data holders have their own metadata catalogue (e.g., CSO, NOCA, HRB).
- Access procedures vary. There is limited infrastructure to connect research queries to data holders. Some links between research bodies and data holders facilitate access (e.g., ESRI and HSE). DASSL project is a technical proof-of-concept on data access, storage, sharing and linkage, due to be concluded in 2022.
- Generally no fees for data access, and national and foreign researchers have the same process.
- Pseudonymisation practices vary, usually in-house.
- There is no health-specific secure processing environment (SPE). The CSO has a SPE, but this is limited in health.
- The lack of a unique identifier implemented consistently across the health system is a barrier to data linkage across different sources. The Health Information Bill will promote the use of the social services number (PPSN) in health, improving the potential for linkage of individual level data.
- A few standards for data exchange are currently in use (e.g., HL7 V2.4, HL7-FHIR, NIMIS for imaging data).
- Semantic interoperability standards in use: ICD-10, aim to transfer to ICD-11. Ireland is a member of SNOMED-CT; a SNOMED-CT Governance Board provides oversight of its implementation.
- HIQA is developing recommendations on a Model for Health Information Standards.

Data governance

- There is currently no health data governance framework, however significant work is ongoing.
- Stakeholders report a need for a body with strategic oversight for primary and secondary use of data.
- A Health Information Bill is being drafted by the Department of Health, aiming to address current challenges and set the policy direction over the next ten years. The objectives include to:
    - Provide legal framework for primary and secondary use of health data
    - Address legal gaps regarding sensitive data
    - Establish a National Health Information Centre
    - Establish a national health information guardian
- HIQA published recommendations on the need for reform of the Irish HIS.
- Consent is needed for research when using health data. The Health Research Consent Declaration Committee (HRCDC) can allow research in the public interest.
- National Office of Research Ethics Committees centralises ethical approval for some research types.
- The CSO's role in health increased during the pandemic, (e.g., COVID-19 Data Research Hub). Difficulties integrating some data types under a Statistics Act.

Resources (human, technical, financial)

- The cyber-attack on the HSE in 2021 means that many financial, technical and human resources are being funnelled into cyber-security.
- There has been increased investment in the ICT infrastructure for health data in recent years.
- Human resource needs:
    - Data analysts/engineers
    - Statisticians
    - Cyber-security experts
    - Software developers
    - Business analysts
    - Information governance knowledge and expertise at national and local level
- Technical resource needs:
    - Development of a secure processing environment for health, and an infrastructure to connect access requests to data holders.

Capacity building

- Examples of training needs:
    - Improved data literacy of healthcare professionals to improve data quality at source
    - Training on robust data governance
- There were several examples of training opportunities across different institutions, such as:
    - Data protection training
    - Training in standards (e.g., ICD-10)
    - Methodological training to researchers on how to use datasets
    - Data quality modules
    - Support to researchers for ethical submissions

Best practices

- The Health Research Consent Declaration Committee (HRCDC) was established in 2018 under the Health Research Regulations. The committee can provide a 'consent declaration', allowing a research project to be carried out without the need for consent, when it is deemed to be in the public interest, facilitating research.
- The Health Information Bill proposes the establishment of a national data guardian, to act as an ombudsman to citizens, representing their views on health data use and re-use.
- The National Office of Research Ethics Committees was established in 2020, and includes the formation of national-level ethics committees for specific types of research. This facilitates research by streamlining the ethics approval process for collaborative studies.
- HIQA developed 'Guidance on a data quality framework', to support organisations to systematically assess, document and improve data quality. The guidance is accompanied by an online learning course to assist its implementation and explain the importance of data quality.

European Health Data Space (EHDS)

- There is strong political will to join the EHDS and a strong recognition of the benefits it can bring. However, stakeholders note that data sharing is currently difficult in Ireland and there are technical and legal issues to be addressed first at national level.
- The national contact point for the secondary use of health data will be a new entity. The upcoming Health Information Bill proposes the formation of the National Health Information Centre, with the aim that it could take on this role.

- Needs for the EHDS:
    - Clear governance of the national HIS, including a data governance framework (e.g., to ensure implementation of data and quality standards)
    - Universal implementation of a unique identifier for health, and ability to link individual level data
    - Harmonised definitions and indicators, structured data, and adoption of standards across private and public providers
    - Legal mandate for data reporting from private providers
- Expectations from the EHDS:
    - EU and local level incentives and enablers for digitalisation
    - EHDS must be relevant for citizens and healthcare providers, demonstrating clear and tangible benefits.